

Genetic Medical Clinic in Kentucky: A Needs Assessment of Anabaptist Households

Matthew L. Hunt
Director, Institute for Rural Health
Western Kentucky University

M. Susan Jones
Professor Emerita, School of Nursing
Institute for Rural Health
Western Kentucky University

M. Eve Main
Professor, School of Nursing
Western Kentucky University

Daniel Carter
Dental Director, Institute for Rural Health
Western Kentucky University

Kevin Cary
GIS Instructor, GIS Center Director
Department of Geography and Geology
Western Kentucky University

Matthew D. Hall
Intern, Institute for Rural Health
Western Kentucky University

Abstract

The purposes of this study are to (a) describe the process of collecting survey data related to un/diagnosed genetic disorders in Anabaptist households, and (b) determine the need for a genetic medical clinic in Kentucky. A six-page adapted survey questionnaire was utilized to collect family status, un/diagnosed genetic conditions, reproductive history, history of deceased children, and demographics. The questionnaire was mailed to over 2,000 households; addresses were collected from Anabaptist directories. Data suggest that more than one-third of households include a family member with an un/diagnosed genetic condition. Collectively, 120 diagnosed conditions and 90 undiagnosed conditions were reported. Half of all households reported a miscarriage, while less than five percent reported a stillbirth. Information obtained from this survey helped Anabaptist leaders proceed with establishing a genetic medical clinic.

Keywords

Genetic Disorders; Mennonite; Amish; WeCare Clinic; Multifactorial Disorders

Acknowledgement

The authors wish to thank Rebecca Evans for sharing her guidance in adapting a survey from the Community Health Clinic, Topeka, IN; Thomas M. Morgan of the Vanderbilt University Medical Center for helping to categorize the self-reported genetic/inherited disorders; the Anabaptist board members who helped guide the survey process; and the survey participants. This project was partly funded by a Western Kentucky University Quick Turn Around Grant.

Address correspondence to: Matthew Hunt, Ed.D.; Western Kentucky University, Institute for Rural Health, College of Health and Human Services, 1906 College Heights Blvd. #21038, Bowling Green, KY 42101; 270-745-4138
matthew.hunt@wku.edu

Recommended citation: Hunt, Matthew L., M. Susan Jones, M. Eve Main, Daniel Carter, Kevin Cary, and Matthew D. Hall. 2018. "Genetic Medical Clinic in Kentucky: A Needs Assessment of Anabaptist Households." *Journal of Amish and Plain Anabaptist Studies* 6(2):159-73.

One such relationship occurred when staff at the Institute for Rural Health (IRH) at Western Kentucky University (WKU) was requested to conduct a survey of Anabaptist households in Kentucky to determine the need for a genetic medical clinic in western Kentucky. This relationship was built on trust and respect, as one of the IRH staff members had a sustained relationship working with a specific Anabaptist community for over 20 years. This long-term relationship provided insight into the health beliefs, values, and practices of the Anabaptist communities, which facilitated planning and conducting the needs assessment.

The purposes of this descriptive study were to: 1) describe the process of collecting survey data from Anabaptist households regarding diagnosed and undiagnosed genetic disorders of members residing in each household, and 2) determine the need to establish a genetic medical clinic in Kentucky.

Background Literature

Historically, in an attempt to escape religious persecution during the Protestant Reformation in the early 18th century, diverse Anabaptist groups such as Amish and Mennonites, migrated to the U.S. and first settled in Lancaster County, Pennsylvania. As the faith and families of the Anabaptist groups grew, so did their desire and need to increase the number of settlements. They initially moved into the Midwestern states but later realized that southern states such as Kentucky provided a suitable social, economic, and geographic environment for growth (Donnermeyer and Anderson 2014).

Kentucky's first Anabaptist settlement was in Todd County in 1958 (Donnermeyer and Anderson 2014). Since then, the majority of growth has occurred in the central, northern, and western regions of the state. In 2017, there was an estimate of 42 Anabaptist settlements, 91 church districts, and a population of 12,060 in Kentucky (Young Center for Anabaptist and Pietist Studies 2017). The rapid growth in Anabaptist settlements could result in a doubling time of 20 years (Donnermeyer and Anderson 2014).

With the anticipated growth of these diverse populations, major health concerns surface. Culturally, individuals from Anabaptist heritage strive to separate themselves from the general society and choose a marriage partner from within their own culture. Marriage tends to occur from remote connections rather than between close cousins (Dorsten, Hotchkiss, and King 1992); however, partners are selected from within the faith. Due to the limited genetic pool, consanguineous marriage has led to inherited genetic disorders, metabolic disorders, and chromosomal disorders (Hostetler 1993; McKusick, Hostettler, and Egeland 1964; Morton, et al. 2003; Puffenberger 2003). The prevalence of these conditions is destined to increase with the continual growth of more Anabaptist communities, thus, supporting the need for specialized genetic health care.

There are now six fully operational clinics specializing in genetic disorders and special needs of the Anabaptists. Two clinics are located in Pennsylvania, two clinics in Ohio, one clinic in Wisconsin, and one clinic in Indiana. Due to the scarcity of these clinics, high patient loads are found in all clinics. Currently, Kentucky Anabaptist families in need of the services offered by one of these genetic medical clinics travel out of state for such specialized health care services. The distance to the clinic and the expense of travel is an obstacle to health care and delays access to care. With improved health care, many of the children diagnosed with an inherited disorder are

now living into adulthood; therefore, the well-established genetic medical clinics first established for children may need to shift their paradigm to incorporate health care across the life span.

The worldview of health among Anabaptist communities is diverse and influenced by cultural values, beliefs, and specific church affiliations. While some communities continue to embrace traditional cultural practices and resist outside Western medical care, other communities with more progressive beliefs are open to some types of modern health care practices (Garrett-Wright, Main and Jones 2016; Kraybill, Johnson-Weiner, and Nolt 2013). With the explosion of scientific discovery in genetics during the past 30 years, Anabaptist communities are faced with complex decisions regarding the acceptance or rejection of modern science. The implications for decisions such as the feasibility of establishing a genetic medical clinic in rural Kentucky are widespread and potentially impact the family and community structure socially, economically, and culturally. Therefore, an unprecedented step was taken when the group of Anabaptist leaders, who are not members of the same religious orders, collaborated and requested a survey to determine the need for a genetic medical clinic in western Kentucky.

Methods

Study design and population

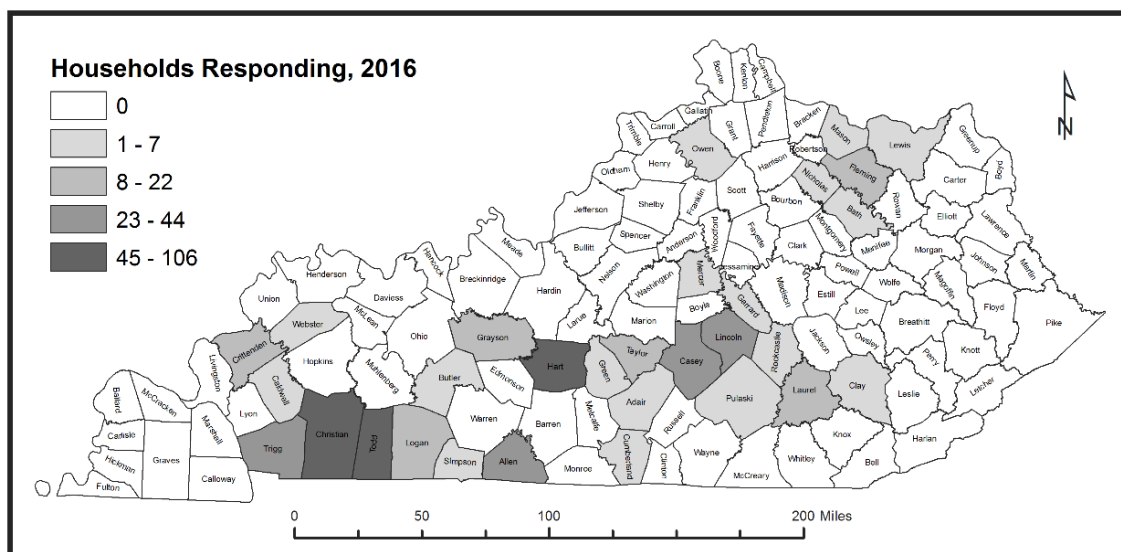
A descriptive study design was used to survey a self-selected sample of adults residing in Anabaptist households in Kentucky. The survey was intended to collect both household and individual information regarding special genetic, metabolic, and chromosomal conditions from the head of the household and individual family members residing in each Anabaptist household.

Recruitment of Sample

A group of five Anabaptist leaders with an interest in establishing a genetic medical clinic in western Kentucky collected church directories throughout Kentucky. The church directories included the names and addresses of Anabaptist households dispersed throughout Kentucky. A pre-medicine, biology student serving as a research assistant at the IRH created a database of the 2,043 addresses prior to mailing questionnaires to all households. The five Anabaptist leaders also visited many of the Anabaptist communities informing the communities that a questionnaire would be forthcoming.

Survey Instrument

A four-page Kentucky Special Needs Clinic Survey questionnaire was adapted from a previously used measurement tool at *The Community Health Clinic* in Topeka, Indiana. The questionnaire contained both open and closed-ended questions designed to solicit information regarding family status, diagnosed and undiagnosed genetic conditions, history of deceased children, and demographics. A two-page sheet containing *Definitions of Genetic Disorders* and explanation of *Frequently Asked Questions* about completing the questionnaire was attached to the questionnaire. The questionnaire was designed so that one adult in each household answered household-level questions and also reported on individual-level responses for all household members.

Figure 2: Map of Sample**Ethical considerations**

Human subjects' protection approval was obtained by Western Kentucky University's Institutional Review Board. Completion of the questionnaire was voluntary and return of the questionnaire indicated the consent of the subjects to participate in the study.

Procedure

Using the names and addresses collected by the five Anabaptist leaders, a database was created by staff at the IRH. The questionnaire, informational sheet, and informed consent document was mailed to 2,043 Anabaptist households in Kentucky. Participants were asked to voluntarily complete the questionnaire and return in a postage-paid return envelope. Funds obtained from an internal university research grant were used to cover expenses associated with data entry, printing, and mailing the questionnaire and consent documents.

Data Analysis

As the questionnaires were returned, data were entered into a Research Electronic Data Capture (REDCap) database and later exported to SPSS 24 software. Descriptive statistics were used to analyze data.

Results**Sample Demographics**

Fifty-one questionnaires were returned marked undeliverable. The questionnaires were completed and returned from 30 (25%) of the Kentucky counties with 550 households (27.61%) completing and returning the questionnaire. Figure 2 is a representative map of households that responded to the questionnaire based on county.

Table 1: Demographics of Respondents from Households

Characteristics	Frequency	Percent
Kentucky Counties Represented	30	25.00
Age of Adults in Household		
0-25	124	11.27
26-50	666	60.55
51-75	236	21.45
76-100	24	2.18
Did not respond	50	4.55
Marital Status		
Yes	520	94.55
No	12	2.18
Did not respond	18	3.27
Children Status		
Yes	510	92.73
No	21	3.82
Did not respond	19	3.45
Number of Children, Including Deceased		
01-03	144	26.18
04-06	163	29.64
07-09	118	21.45
10-12	59	10.73
13-15	12	2.18
16+	3	0.55
Did not respond	51	9.27
Number of People in Household		
01-03	123	22.36
04-06	190	34.55
07-09	132	24.00
10-12	63	11.45
13-15	10	1.82
16+	1	0.18
Did not respond	31	5.64

N = 550

Table 1 shows the demographic characteristics of the survey sample. Males in the sample ranged in age from 21 to 95 years while the age range for females was 20 to 94 years. The majority of the sample were married (94.55%), with children (92.73%). The number of children in each household including the deceased ranged from 1 to 18.

Table 2: Reported Diagnosed Genetic Disorders*

A to E	F to M	N to Z
Attention Deficit Disorder	Factor V Deficiency	Nephritic Syndrome
Alpha #1 Antitrypsin Deficiency	Factor V Leiden	Neurofibromatosis Type 1
Anorectal Atresia	Glucose-Galactose Malabsorption	Neural Tube Defect
Ankylosing Spondylitis	GM3 Synthase Deficiency	Obsessive-Compulsive Disorder
Aortic Stenosis	Hashimoto's Thyroiditis	Optic Nerve Hypoplasia
Asthma	Hearing Impairment	Osteogenesis Imperfecta
Autism Spectrum Disorder	Hearing Loss	Partial Trisomy
Brain Aneurism	Heart Defect	Phenylketonuria
Brain Tumor	Heart Murmur	Polycystic Ovarian Syndrome
Carbohydrate Intolerance	Hereditary Spherocytosis	Polycythemia Vera
Carrier of Tight Junction Protein 2 Gene	Hirschsprung's Disease	Protein C Deficiency
Celiac Disease	Hole in Heart (valve not closed)	Pulmonary Hypertension
Cerebral Palsy	Holoprosencephaly	Rett Syndrome
Cleft Lip	Hypertrophic Cardiomyopathy	Rheumatic Fever
Clubfoot	Hypoplastic Left Heart Syndrome	Syndrome of Short Stature, Auditory-Canal Atresia, Mandibular Hypoplasia, and Skeletal Abnormalities
Coarctation of the Lower Aorta	Hypopadias	Seasonal Allergies
Colon Cancer	Hypothyroidism	Seizure Disorder
Compound Genetic Mutation	Innocent Heart Murmur	Sickle Cell Anemia
Crigler-Najjar Syndrome	Kidney Defect	Spina Bifida
Crohn's Disease	Legs and Hands Deformity	Systemic Lupus Erythematosus
Cytomegalovirus	Leukodystrophy	Thyroid Cancer
Deletion of 118 Genes of Chromosome 1	Lynch Syndrome	Trisomy 13
Diabetes	Maple Syrup Urine Disease	Vertebral Defects, Anal Atresia, Cardiac Defects, Tracheo-esophageal Fistula, Renal Anomalies, and Limb Abnormalities Association
Diastolic Dysfunction	Medium Chain Acyl CoA Dehydrogenase	Vasculitis
DiGeorge Syndrome	Deficiency	Ventricular Septal Defect
Down Syndrome	Meningitis	Wolff-Parkinson-White Syndrome
Duodenal Stenosis	Microcephaly	
Dyslexia	Moyamoya Disease	
Eczema	Musculoskeletal Disorder	
Encephalitis	Methylenetetrahydrofolate Reductase	
Erythema	Gene Mutation	
Ellis-van Creveld Syndrome	Myocarditis	
Extra Circuit (Cardiac Conduction Disorder)		

**Of the 89 diagnosed genetic disorders reported in Table 2, some were reported multiple times for a total of 120 reported diagnosed genetic conditions*

Table 3: Reported Undiagnosed Genetic Disorders*

A to F	G to N	O to Z
Acid Reflux	Gluten Intolerance	Osteosclerosis
Attention Deficit Disorder	Growth Retardation	Ornithine Transcarbamylase Deficiency
Attention Deficit/Hyperactivity Disorder	Headache	Pectus Excavatum
Atypical Hemolytic Uremic Syndrome	Hepatoblastoma	Retardation
Allergies	High Blood Pressure	Scoliosis
Anorexia Nervosa	Hydrocephalus	Seizure Disorder
Anxiety	Hyperactivity	Sinus Problems
Asthma	Hypothyroidism	Small for Gestational Age
Autistic Actions	Inability to Focus	Slow Learner
Bipolar Disorder	Inflammatory Disorder	Small Ear Canal
Cancer	Kidney Problems	Small for Age
Cohen Syndrome	Low Adrenal Function	Tachycardia
Craniosynostosis	Low Blood Sugar	Triangular Shaped Face
Dairy Intolerance	Low Muscle Tone	Unable to Cope with Stress
Deafness, Unilateral	Memory Loss	Unable to Express Oneself
Delayed Growth Physically and Mentally	Meniere's Disease	Vertigo
Dementia	Muscular Dystrophy	Zellweger Syndrome
Depression	Myasthenia Gravis	
Diabetes	Neurological Damage Caused	
Eye Muscle and Vision Problems	from Lack of Oxygen	
Failure to Thrive	Non-verbal	
Fatigue		
Female Problems		

**Of the 60 undiagnosed genetic disorders reported in Table 3, some were reported multiple times for a total of 90 reported undiagnosed genetic conditions.*

Table 4: Genetic Disorders

Amish/Mennonite Endemic* (OMIM)**	Amish / Mennonite Non-endemic	Chromosomal Disorder Sporadic / Non-endemic
Alpha-1 Antitrypsin Deficiency (107400) Amish Infantile Epilepsy Syndrome (GM3 Synthase Deficiency; #609056) Cohen Syndrome (#216550) Crigler Najjar Syndrome (#218800) Ellis-van Creveld Syndrome (#225500) Glucose-Galactose Malabsorption (#606824) Hereditary Spherocytosis (Morton 2003) Hirschsprung's Disease (#600155) Hypertrophic Cardiomyopathy [3] (*600958) Leukodystrophy (#608804) Maple Syrup Urine Disease (2) (#248600)	Atypical Hemolytic-Uremic Syndrome DiGeorge Syndrome (22q11.2 deletion) Factor V Leiden [2] Lynch Syndrome Neurofibromatosis-1 Ornithine Transcarbamylase Deficiency Protein C Deficiency Rett Syndrome Sickle Cell Anemia	Down Syndrome Chromosome 1 Deletion (118 genes) Partial Trisomy (unspecified chromosome) Trisomy 13
Medium Chain Acyl CoA Dehydrogenase Deficiency (2) (#201450) Methylenetetrahydrofolate Reductase Deficiency (#236250) Osteogenesis Imperfecta (#166200) Osteosclerosis (Van Buchem Disease #239100) Phenylketonuria (+261600) Progressive Familial Intrahepatic Cholestasis (unaffected carrier TJP mutation #211600)		

*Endemic defined as disorder nominally present in Amish, Mennonite, and Hutterite Genetic Disorder Database (<http://www.biochemgenetics.ca/plainpeople/index.php>) and/or found in Morton (2003 PMID: 12888982) and/or Strauss (2009 PMID: 19630565).

**OMIM number refers to Online Mendelian Inheritance in Man unique reference number (www.omim.org)

Findings

Of the 550 returned questionnaires, 200 (36.36%) of the households reported a known or suspected genetic disorder. In response to diagnosed conditions, 64 of the households reported that the husband, wife, or children had been diagnosed by a doctor with a genetic disorder, an inherited disorder, and/or a metabolic disorder. Only 46 of the households reported that a birth defect had been diagnosed by a doctor in the husband, wife, or children, and only six of the households indicated that anyone in the household had been diagnosed with autism and or an autism spectrum disorder.

In response to the open-ended question regarding the specific name of diagnosed and undiagnosed genetic conditions in the household, Table 2 shows the 89 diagnosed conditions that were recorded while Table 3 shows the 61 undiagnosed conditions that were reported by the households. A physician with expertise in genetics later categorized both the diagnosed and undiagnosed self-reported data into the groupings: 1) genetic and chromosomal disorders known to be associated with Anabaptist populations (Table 4), 2) overview of multifactorial disorders (Table 5), and 3) overview of miscellaneous signs and symptoms (Table 6). Multifactorial disorders are defined as conditions in which environmental factors may influence the variation in the expression of a genetic trait (Jorde 2014).

Table 5: Overview of Multifactorial Disorders

A to D	E to M	N to Z
Allergies	Eczema	Nephritic Syndrome
Ankylosing Spondylitis	Encephalitis	Neural Tube Defect
Anorectal Atresia	Fetal Alcohol Syndrome	Obsessive-Compulsive Disorder
Anorexia Nervosa	Gastroesophageal Reflux	Optic Nerve Hypoplasia
Aortic Stenosis	Gluten Intolerance	Pectus Excavatum
Asthma	Hashimoto Thyroiditis	Polycystic Ovarian Syndrome
Attention Deficit Disorder	Hepatoblastoma	Polycythemia Vera
Autism Spectrum Disorder	High Blood Pressure	Pulmonary Hypertension
Bipolar Disorder	Holoprosencephaly	Rheumatic Fever
Brain Aneurysm	Hydrocephalus	Scoliosis
Brain Tumor	Hypoplastic Left Heart Syndrome	Seasonal Allergies
Cardiac Septa Defect	Hypothyroidism	Seizures
Celiac Disease	Hypospadias	Small for Gestational Age
Cerebral Palsy	Hypoxic-Ischemic Encephalopathy	Spina Bifida
Cleft Lip	Kidney Defect	Systemic Lupus Erythematosus
Clubfoot	Lactose Intolerance	Thyroid Cancer
Coarctation of the Lower Aorta	Meniere's Disease	Vertebral Defects, Anal Atresia,
Craniosynostosis	Meningitis	Cardiac Defects, Tracheo-Esophageal
Crohn's Disease	Microcephaly	Fistula, Renal Anomalies, and Limb
Cytomegalovirus	Moyamoya Disease	Abnormalities Association
Colon Cancer	Myasthenia Gravis	Ventricular Septal Defect
Deafness, Unilateral	Myocarditis	Vasculitis
Dementia	Muscular Dystrophy	Wolff-Parkinson-White Syndrome
Depression		Zellweger Syndrome
Diabetes		
Diastolic Dysfunction		
Duodenal Stenosis		
Dyslexia		

Reproductive history findings as reported by the households are presented in Table 7. Miscarriages were reported by 265 (48.18%) of the households with the number of miscarriages ranging from 1 to 11. Stillborn children were reported by 27 (4.91%) of the households.

Discussion

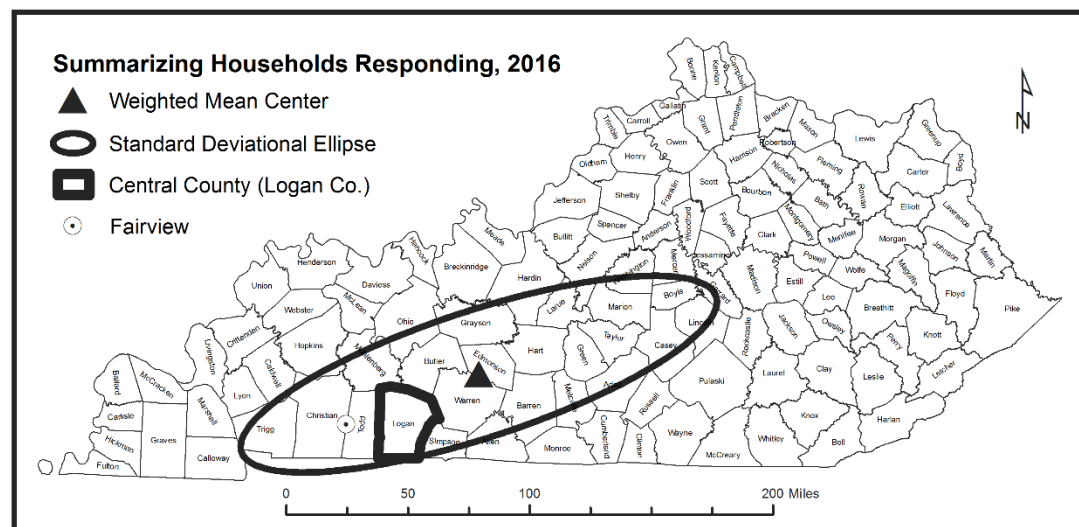
For communities that prefer separation from the modern world, a return rate of 27.61% for the questionnaire is consistent with the return rate of other cross-sectional surveys in Anabaptist communities (Sieren, et al. 2016). Several actions contributed to this success. First, the group of Anabaptist leaders through dialogue among themselves and with individuals from English communities kept their vision alive from the initial meeting in 2009 to 2016. Also, prior to mailing the questionnaire, this group of leaders visited the Anabaptist communities in Kentucky collecting names and addresses and alerting the communities that the questionnaires would be forthcoming. In addition, a cover letter was included with the questionnaire that was signed by one of the five Anabaptist leaders and a staff person in the IRH whose name might have been

Table 6: Overview of Miscellaneous Signs/Symptoms

A to K	L to Z
Anxiety	Lack of Ability to Focus
Autistic Actions	Legs and Hands Deformity
Carbohydrate Intolerance	Low Adrenal Function
Compound Genetic Mutation	Low Blood Sugar
Delayed Growth Physically and Mentally	Low Muscle Tone
Extra Circuit (Cardiac Conduction Disorder)	Memory Loss
Eye Muscle and Vision Problems	Musculoskeletal Disorder
Failure to Thrive	Non-verbal
Fatigue	Racing Heart
Female Problems	Syndrome of Short Stature, Auditory-Canal Atresia, Mandibular Hypoplasia, and Skeletal Abnormalities
Genetic Cancer	
Growth Retardation	Social Hyperactivity
Headache	Sinus Problems
Heart Defect	Slight Retardation
Heart Murmur	Slow Learner
Hyperactive	Small Ear Canal
Inflammatory Disorder	Small for Age
Innocent Heart Murmur	Triangular Shaped Face
Kidney Problem	Unable to Cope with Stress
	Unable to Express Oneself
	Vertigo

Table 7: Reproductive History of Respondents from Households

Characteristics	Frequency	Percent
Miscarriages		
Yes	265	48.18
No	245	44.55
Did not respond	40	7.27
Number of Miscarriages Per Households		
1-2	185	33.64
3-4	36	6.54
5-6	10	1.82
7-8	4	0.73
9-10	1	0.18
11+	1	0.18
Did not respond	313	56.91
Stillborn Children		
Yes	27	4.91
No	478	86.91
Did not respond	45	8.18

Figure 3: Map Summarizing Location of Households

recognized by members in some communities. It is also expected that some households returned the questionnaire out of duty to their neighbors and communities.

Figure 3 is a summary of the geographic distribution of the households that responded to the questionnaire in 2016. Using only counties in Kentucky with at least one household respondent, the geographic weighted mean center, or “center of gravity,” of respondents is located in southcentral Kentucky, between Warren County and Edmonson County. A standard deviational ellipse is drawn around the geographic weighted mean center that encompasses 85% of the respondents. The spatial dispersion is skewed eastward/westward, but includes eight of the top ten counties of respondents (see Figure 3). By using county level data and not using precise locations, it is speculated that the standard deviational ellipse may actually encompass 68% of the respondents’ absolute locations. The most central county that minimizes the distance between itself and the respondents is Logan County, Kentucky.

Over one-third of the households self-reported a known (diagnosed) or suspected (undiagnosed) genetic disorder. These survey results of diagnosed conditions were classified into genetic disorders known to be prevalent among the Anabaptists. It is unknown if the diagnosed diseases are the Anabaptist form of the disorder in each case, but it is reasonable to classify these as known or suspected endemic among Anabaptist populations. The next step needed to further understand the genetic disorders present in Kentucky is to conduct a medical review with Anabaptist families residing in the state. The medical review would serve as a gold-standard review to learn more about the special health care needs and health histories of each family.

While the exact number of genetic conditions in Kentucky Anabaptist households is not determined from these survey results, findings do support some practical implications. Many women experience home births attended by lay midwives. With the alarming number of miscarriages and reports of stillbirths, the lay midwife may be the first contact with the infant and family with genetic disorders. Therefore, improving access to newborn screenings and increased parental acceptance of such screening is needed (Sieren, et al. 2016). In addition,

Figure 4: WeCare Clinic – Medical Care for Special Needs



educational programs and resources to assist these lay midwives in recognizing signs and symptoms of genetic disorders at birth thus enabling them to make quick referrals is warranted.

The first genetic medical clinics rightfully focused on care of children with genetic disorders. With advancements in modern medicine, children with genetic disorders now mature into adulthood but continue to need knowledgeable health care providers to direct their health care. A patient and family centered medical home framework identifies the importance of family in care coordination. The characteristics of the framework include patience and a family-centered focus; care activities that are proactive, planned, and comprehensive; the promotion of self-care skills and independence; and the importance of cross-organizational relationships (Turchi, et al. 2014).

Strengths and Limitations

Strengths of the survey process include the collaborative relationship between the Anabaptist leaders and the research team. This relationship along with open communication fostered access to sensitive information from a population that is generally cautious about interactions with the mainstream culture. Another strength of the survey process was the capturing of rich health-related data for an entire household in lieu of getting individual responses. Two limitations of the survey process would be the questionable validity of the self-reported data and this non-random sample is not generalizable to the Amish population.

Conclusion

The needs assessment demonstrated a population that could benefit from a genetic medical clinic in Kentucky by improving access to specialty care within their community. With less than one-third of the potential sample participating in the Kentucky survey and the lack of surveying Anabaptists in surrounding states, the need for such a clinic is most likely underestimated. In addition, the intent of the survey was to identify children with genetic disorders. One would

anticipate a need for special genetic medical consultation or care for the parents of these children who are living with or carriers of specific genetic disorders.

Epilogue

The process of conducting the survey provided momentum for the Anabaptist leaders to gain support to ensure that the vision for the genetic medical clinic would transition into a reality. Based on the geographic distribution of households, a genetic medical clinic location in close proximity to Logan County, Kentucky was affirmed as an ideal setting to for the clinic. Examples of progress toward establishing a genetic medical clinic include completing the necessary steps for certificate of need from the state of Kentucky, acquiring 501c3 status as a non-profit organization, and purchasing and renovating the future clinic building, named the WeCare Clinic – Medical Care for Special Needs (WeCare) (Figure 4). Plans are to host an inaugural Family Genetic Disease Day at the clinic site to gather more details about the specific genetic diseases and learn more about the questions that the Anabaptist families have about their health and the health care system.

In addition to the board of directors for WeCare, the board formed a working group consisting of leaders in the various Anabaptist settlements to serve as community contacts. The community contacts have served as a resource to bridge the gap between WeCare and the settlements in the state. Meetings involving the board of directors and the community contacts have been used to keep the various settlements dispersed throughout the state updated on the progress of the clinic. Furthermore, quarterly newsletters along with meetings with health professionals residing in close proximity to the clinic site have been used as strategies to keep the medical community abreast of work done on behalf of the clinic. Collaborative efforts have extended beyond the Anabaptist leaders as the first annual auction was held with money received throughout Kentucky to support the cause. Donations for the clinic have also been made from other states with Anabaptist settlements. Also, many Anabaptist members donated their time and construction skills to assist with renovation of the building. Communications with Dr. Morton, staff from the other genetic medical clinics, and board members from the other genetic medical clinics have allowed WeCare to benefit from prior learned lessons regarding the best practices and models of care.

The specific model of care to be implemented at WeCare is taking shape with the goal for the patient to remain at home when possible but have access to genetic medical care when needed. The board of directors of WeCare is forming a relationship with a large, research-based children's hospital for care that is needed beyond the scope of care available at WeCare. The goal is for a sustainable model of care that incorporates best practices at the most reasonable cost. Also needed is a model of care that fosters midwife education focused on the initial signs and symptoms of genetic disorders and implications for early referral.

The lasting impact of the needs assessment extends beyond the physical clinic building. New relationships have been created and fostered between the Anabaptist members, Western Kentucky University, and Vanderbilt University Medical Center. The shared goal of these relationships is to improve community health, improve the quality of health care for patients and families, and reduce medical costs.

References

- Donnermeyer, Joseph, and Cory Anderson. 2014. "The Growth of Amish and Plain Anabaptist in Kentucky." *Journal of Amish and Plain Anabaptist Studies* 2(2):215-44. <https://doi.org/10.18061/1811/63996>
- Dorsten, Linda Eberst, Lawrence Hotchkiss, and Terri King. 1999. "The Effect of Inbreeding on Early Childhood Mortality: Twelve Generations of an Amish Settlement." *Demography* 36(2):263-71. <https://doi.org/10.2307/2648113>
- Garrett-Wright, Dawn, M. Eve Main, and M. Susan Jones. 2016. "Anabaptist Community Members' Perceptions and Perceptions Related to Healthcare." *Journal of Amish and Plain Anabaptist Studies* 4(2):187-200. <https://doi.org/10.18061/1811/79932>
- Hostettler, John. 1993. *Amish Society*. Baltimore, MD: The Johns Hopkins University Press.
- Jorde, L. B. 2014. "Genes, Environment-Lifestyle, and Common Diseases." Pp. 164-70 in *Pathophysiology: The Biologic Basis for Disease in Adults and Children*, edited by K. McCance & S. Huether. St. Louis, IL: Elsevier Mosby.
- Kraybill, Donald, Karen Johnson-Weiner, and Steven Nolt. 2013. *The Amish*. Baltimore, MD: Johns Hopkins University Press.
- McKusick, Victor, John Hostettler and Janice. Egeland. 1964. "Genetic Studies of the Amish: Background and Potentialities." *Bulletin of the Johns Hopkins Hospital* (115):203-22.
- Morton, D. Holmes, Caroline Morton, Kevin Strauss, Donna Robinson, Erik Puffenberger, Christine Hendrickson, and Richard Kelley. 2003. "Pediatric Medicine and the Genetic Disorders of the Amish and Mennonite People of Pennsylvania." *American Journal of Medical Genetics Part C: Seminars in Medical Genetics* 121C(1):5-17. <https://doi.org/10.1002/ajmg.c.20002>
- Puffenberger, Erik. 2003. "Genetic Heritage of the Old Order Mennonites of Southeastern Pennsylvania." *American Journal of Medical Genetics Part C: Seminars in Medical Genetics* 121C(1):18-31. <https://doi.org/10.1002/ajmg.c.20003>
- Sieren, Shelby, Meghan Grow, Matthew Good Smith, Gretchen Spicer, James Deline, Qianqian Zhao, Mary Lindstrom, Anne Bradford Harris, Angela Rohan, and Christine Seroogy. 2016. "Cross-Sectional Survey on Newborn Screening in Wisconsin Amish and Mennonite Communities." *Journal of Community Health* 41(2):282-88. <https://doi.org/10.1007/s10900-015-0094-1>
- Turchi, R. M., R.C. Antonelli, K.W. Norwood, R.C. Adams, T.J. Brei, R.T. Burke, and S.E. Levy. 2014. "Patient-and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth across Multiple Systems." *Pediatrics* 133(5):e1451-e1460. <https://doi.org/10.1542/peds.2014-0318>
- Young Center for Anabaptist and Pietist Studies. 2017. "Amish Population Profile, 2017." Elizabethtown College. Retrieved March 22, 2018 (<http://groups.etown.edu/amishstudies/statistics/amish-population-profile-2017>).